

Forsde

PHoenix Rising Publication
#1

MYTHS OF MENTAL ILLNESS

by

Carla McKague

MYTHS OF MENTAL ILLNESS

(Transcript of an invited address by Carla McKague to the Kingston chapter of the Canadian Mental Health Association on September 27, 1979. Carla is a third year law student at the University of Toronto, a former psychiatric patient, and a member of the Boards of Directors of: the Ontario Patients' Self-Help Association (an independent non-profit group of former psychiatric patients); HouseLink Community Homes (a non-profit organization helping former psychiatric patients set up cooperative living arrangements); and ARCH (Advocacy Resource Centre for the Handicapped--an organization providing legal and advocacy services to handicapped people).

The reason that all of us are here, you and me, is a gigantic problem. Some of you are aware of the dimensions of the problem; some of you may not be fully aware. Let me start by giving you a little bit of an idea.

Right now, this moment, there are 50,000 Canadians in mental hospitals. Tomorrow, another 30,000 to 50,000 will be showing up either at out-patient clinics or at private psychiatrists' offices. Every year 130,000 Canadians enter psychiatric institutions, and about two-thirds of them are coming back; they've been there before, and they're back. At least one in ten Canadians can expect at some time in his or her life to spend time in a psychiatric institution. And, to switch to financial terms, the cost of maintaining those institutions in Canada is approximately a million dollars a day. That's the size of the problem we're facing.

Now, I don't know most of you sitting in front of me. I'm not sure why you're here as individuals. I can make some guesses. Some of you are people who work professionally in the field of "mental illness"; you may be doctors, nurses or social workers who are concerned about the problem. Some of you are plainly and simply--and importantly--members of the community who are aware that there's a problem and would like to help do something about it. Some of you have had the experience yourselves of being patients, or have had someone in your family have that experience. You're probably concerned; you're probably confused; you're probably not quite sure what it is that's happened to you, and why it's happened, and what you can do about it.

The reason that I'm here speaking to you is because I'm also a person who's very concerned, concerned enough to be a part of three different organizations dealing with three different aspects of the problems of patients and former patients. I'm someone who's concerned about the legal aspects of the problem, and putting myself through legal training to enable me to perhaps do something about some of those aspects.

But the most important qualification I have for speaking to you is that I've been a patient myself. I spent six months a number of years ago in two psychiatric institutions. I've been through two serious episodes of depression since. I know what it feels like, what it looks like from the other side. And what it looks like very often from the other side is that the people out there have almost no understanding of what is going on. There are a number of misunderstandings, false ideas, myths--whatever you'd like to call them--beliefs that just aren't so about what it means to be someone with emotional problems. And what I'd like to do tonight is to try to talk about some of those myths.

The first myth--and an important one with respect to the relationship between "mental patients" and the community--is the myth that "mental patients" are dangerous and violent people. I think the newspapers and the other media are largely responsible for this. I'd like you to think back to the last time you saw the words "mental patient" or "psychiatric patient" in a newspaper. What were they coupled with? It was probably "Mental Patient Kills Child" . . . "Mental Patient Beats Up Wife" . . . "Mental Patient Drives Car Into Telephone Pole". When is the last time--to steal a line from Judi Chamberlin's book "On Our Own"--that you saw a headline that read "Mental Patient Elected Head of House and Garden Club"? When I graduate from law school next year, is there going to be a headline that says "Mental Patient Graduates From Law School"? The only time those words appear in print, in the media, is in connection with violence. So of course everybody thinks "mental patients" are violent.

Now there have been a number of studies done on relative rates of violence. Every single study that has ever been done has shown that the rate of violence among people who have been in mental hospitals is lower than among the general population--anywhere from two to fourteen times as low. So if we take a nice safe number--say five times as low--then, given the fact that one out of ten Canadians is going to be in the position of being an ex-patient, if you're assaulted it's fifty times as likely to be by a non-patient as by a patient.

A second myth that goes along with this--given the fact that of course some patients are violent--is the myth that psychiatrists can somehow tell who the patients are that are going to be violent. Again, there have been a number of studies done, and in every case psychiatrists have been shown to be no more adept than the general public at making that sort of prediction. In fact, they tend to grossly over-predict, to say many more people are going to be dangerous than is in fact the case. The most famous illustration of this is something that happened in the United States ten or fifteen years ago. As a result of a lawsuit, a hospital in the United States--a hospital which was similar to Oak Ridge here in Canada, a hospital for the "criminally insane" whose patients were considered to be among the most dangerous and violent people in the state--had to release 969 patients. The psychiatrists were tearing their hair out; they were saying, "We're going to have them all back within two months! They're going to rape and murder and steal and do terrible things! What are you letting them out for?" Four and a half years later, they had twenty-six back; the other 943 were doing just fine.

The American Psychiatric Association--which is much more honest about this than the Canadian Psychiatric Association--has in fact officially stated: "Psychiatric expertise in the prediction of dangerousness is not established, and clinicians should avoid conclusory judgments in this regard."

Along with the myth that psychiatrists know who's going to be violent is the myth that psychiatrists can in fact make accurate diagnoses of patients in the first place. I'd like to mention briefly a study done by a professor of psychology at Stanford University named Rosenhan. He and a number of graduate students decided to do a little experiment on how well psychiatrists can diagnose. They presented themselves without warning at a number of large mental hospitals and announced to the admitting psychiatrists that they were hearing voices saying things like "hollow" and "thud". Now this particular "symptom" is symptomatic of absolutely nothing. It has no known psychiatric diagnosis. They were, however, all promptly admitted to hospital. They didn't lie about anything else--they gave their real names, they gave their true family histories, and within a day after they were admitted they all said, "I've stopped hearing the voices now." They were kept in for an average of two weeks; they were all diagnosed as "schizophrenic"; and when they were finally discharged, they were discharged not as "not ill" but as "schizophrenic in remission". During the time they were in hospital they quite openly took notes on their experiences; this was considered to be a "symptom".

The National Institute of Mental Health--again a little more honest than some of our Canadian institutions--in one of their bulletins a few years ago stated quite flatly: "It is not possible to validate a diagnosis of schizophrenia. There is no test which can independently confirm that the individual so diagnosed is in fact schizophrenic." My favourite diagnosis of those I've run across is of a person who obviously the doctor desperately wanted to find something wrong with, but there were no symptoms. So he was diagnosed as suffering from "pseudo-neurotic schizophrenia". This was explained as "He has schizophrenia, but he's hiding the symptoms." As another small example of the accuracy of psychiatric diagnosis, I would point you to any newspaper report of any court case in which there are psychiatrists called by both sides--try to find two psychiatrists on opposite sides of a court case who agree with each other.

A fourth myth is that psychiatric treatment is effective and safe--that it actually cures people and doesn't hurt them. As far as actually "curing" goes, you need only look

at the readmission figures which I mentioned before. Out of all the Canadians who go into hospital this year, roughly two-thirds are coming back; they've been there before, they've been out, and now they're back in. As far as the safety of psychiatric treatment is concerned, there is no doubt that many, many of the treatments that are used in our mental hospitals have extremely serious "side effects". In fact, it's a misnomer to call them side effects; they're direct effects. They're called side effects only because that's not the primary aim of giving the treatment. For instance, take the more potent tranquillizers that we have--with which we do not cure people, but manage to mask their symptoms enough that they can walk around. Of the people who are on some of these more potent tranquillizers for six months or more, between 25% and 40% develop a particularly nasty reaction known as tardive dyskinesia--a gradual degeneration of the central nervous system resulting in involuntary tics, tremors, a tongue that hangs out of the side of your mouth, and a neck that twists to the side. It is generally irreversible. Large numbers of drugs--not to the same extent as thalidomide but to some extent--are responsible for birth defects when given to pregnant women. These are only a few examples.

Another psychiatric treatment which has enjoyed widespread use in the hospitals--less now that the major tranquillizers have begun to take over--is electro-convulsive therapy. There are a large number of doctors who swear by it as a cure, usually for depression, sometimes for schizophrenia, sometimes for other things. There have been exactly four double-blind studies done on electroconvulsive therapy since it was first used forty years ago. Those four studies all came out negative, saying that there was no proven benefit from the treatment. But what there is proven is: brain damage, memory loss, cardiovascular complications, impotence, broken bones, fetal death, on and on and on--and death. There have been almost 400 reported deaths from ECT in the medical literature--there's no telling how many unreported--and from a treatment of dubious, if any, benefit.

Myth Number Five is that if you're ill, our psychiatric institutions are a good place to go. Well, I've given you my views on the medical treatment you get in a psychiatric institution. I point out that in the largest institution in Toronto in 1972, there were sixteen suicides. I also point

out a report to the British Columbia government in 1974 which recommended that every large mental institution in that province should be demolished within the next five years.

I'd also like to give you just a couple of little personal experiences of my own. When I was hospitalized, one of the nice things they gave you--and still give you--in hospital along with medical treatment was "therapy"--there's "occupational therapy", "vocational therapy", it comes in a number of guises. I was hospitalized because I was acutely depressed, to the point where I could barely function. One of the things I wasn't functioning too well at was housework. "Vocational therapy" consisted of having me go down to the men's ward in the hospital and scrub the tables in the men's dining room. Somehow this was going to "cure" me.

The other experience ties in with Myth Number Six--that in fact psychiatric patients continue to have the same kind of rights as other people. I was also hospitalized last summer for a different reason, a non-psychiatric reason. I had a suspected neurological problem, and as a consequence the hospital I was admitted to was a psychiatric hospital, because that was where they were equipped to do the neurological tests. As I arrived on the ward, my greeting was, "Of course, dear, you'll have full privileges." What this meant was that I was going to be allowed to wear my own clothes, I was going to be allowed to use the telephone, to leave the ward to go for a walk, to have visitors. I don't think those are "privileges". I think if I hadn't had those, it would mean that somebody was taking away my rights. Why should someone who is supposedly "ill" and in a "hospital" be deprived of such things as wearing her own clothing, being able to make a telephone call, having a visitor, getting a letter without having it opened on the way in? Those are not "privileges".

There are some more important rights, though, that you lose when you're in a psychiatric hospital. First of all, how do you get in there? Sometimes by choice. More often because you have to. Somebody commits you. Somebody says, "You must go here." If one of you were to go out and get a gun and shoot somebody, you would have a trial before you lost your liberty. You would have a judge, a courtroom, a

public hearing to decide whether it was fair for you to be deprived of your liberty or not. If you're judged to be "mentally ill", you lose that right. All it takes is the signature of two doctors, and you're in. You have a right to appeal to a Review Board, but the Review Board does not even have to let you be present at the hearing. You have no right to see your medical records--they can see your records, but you can't. A murderer, a child molester, a rapist, gets far, far more protection than someone who is judged to be "mentally ill".

And once you're in there, technically you have a right to refuse treatment, as all medical patients do. If you have cancer and you say, "Don't give me any treatment," the doctor can't give you any treatment. A "mental patient" has that right too, on paper, but there's a catch. What the doctor can do is declare that you're "mentally incompetent" to make a decision and treat you anyway. And, of course, the person who's deciding if you're "competent" or not is the same person who wants you to have the treatment. Obviously, if you're refusing to have the treatment he thinks you should have, you're "incompetent" and you can be overridden.

All of this has been leading up to what is in my mind the major myth of mental illness, and that's the one I'd like to end this talk with. And that is that "mental illness" is in fact a disease, an illness. I'm not suggesting that the people we call "mentally ill" have nothing wrong with them. Most certainly do; they have serious problems, serious troubles. Where I draw the line is at calling that an "illness". An illness has specific symptoms, specific causes, a reasonably definite and predictable course, and very often a cure. "Mental illness" meets none of these criteria. It can appear for no apparent reason; it can take any number of unpredictable directions; and there are usually no organic manifestations. For some forms there are--you can look and say, "Aha, there's a tumour in the brain that's causing this behaviour." Fine--I'm willing to call that an illness. But if there's nothing you can see with your EEGs and your X-rays and your blood tests and everything else, that's not a disease--it's a problem.

Now, I'm not suggesting that all of these highly trained medical people are running around treating something that isn't a disease and knowing it. I'm suggesting that they have been brainwashed into seeing it as a disease. I suspect that during the Inquisition the people who were burning witches believed in witches. So I'm not accusing psychiatrists and medical staff of bad faith.

But I'd like to tell you about a fascinating paper. In 1851, the President of the Louisiana Medical Association was a certain Dr. Cartwright. And at the Annual Meeting of the Louisiana Medical Association that year, Dr. Cartwright read a paper to the Association in which he identified two new "mental illnesses". One of these he called "drapetomania"; the symptom was that slaves who had drapetomania tended to run away from their masters. The other was called "dyaesthesia aethiopiuis"; the symptom here was that the slave wouldn't work. He even had cures for these. The cure for drapetomania was whipping. The cure for dyaesthesia aethiopiuis was "to have the patient well washed with warm water and soap, then to anoint him all over with oil and to slap the oil in with a broad leather strap, then to put him to some hard kind of work in the open air and sunshine." I suspect these "cures" worked. I suspect we get a lot of "cures" in psychiatric hospitals for much the same reasons.

One of the reasons that most of you are here is to ask, "What can we as a community do to help these people?"--who, for the sake of convenience, I will continue to call "mental patients". They--we--have some very real and important needs. The needs are not for electroconvulsive therapy and drugging, or labelling, or pity, or fear. What we need first of all is friendship, understanding, people who do not shy away from us because they don't quite understand us and we're a little bit different from the rest. We need a place to live. We need a job. One of the reasons many people end up back in hospital is the frustration of trying to get such simple things as a place to live and a job. We need legal protection; it should be harder, not easier, for people to be forcibly hospitalized or forcibly treated. And mostly what we need is recognition that we're not some strange breed. We're people, we're human beings, we're the same as you except that maybe we have a few more problems. As R. D. Laing has pointed out, if someone is disturbed, it's very probable that there's something disturbing him.

DISCUSSION PERIOD

- Q. That statistic that two-thirds of people coming into hospital are coming back--do you think that's because of being beaten down when you were in before? Or is it largely that the community labels you, and you're so isolated?
- A. I think it's a complex of things. Part of it is the difficulties when you get out--no job, no place to live, and it's quite possible family and friends have turned their backs on you and don't want to have much to do with you any more. Another factor which I didn't mention is the phenomenon of institutionalization. Anyone who's spent any length of time in a psychiatric hospital --or a prison or other similar place--ends up coming out really infantilized in a lot of ways. They can spend months asking permission to do anything: "Can I use the phone?" "Can I have a cup of coffee?" "Can I go to the bathroom?" They can't do anything on their own because they've forgotten how. Everybody has been deciding everything for them for so long that coping with having to run their own lives becomes a really serious problem. And sometimes they simply retreat back to where somebody else is going to make the decisions for them.
- Q. I recall a comment about hospitals, in this case general hospitals. Basically, when you check into a hospital, they ask you to check in your brains along with your clothes. . . .
- A. Well, in a psychiatric hospital, of course, the assumption is that you have no brains to check.
- Q. Once you're labelled a "mental patient", wouldn't you probably carry that out and act the way everybody believes the "mentally ill" act?
- A. Oh, certainly. It's a losing battle and you give up. You get the phenomenon which I think I mentioned briefly in passing. If I say you're "schizophrenic", and I'm a doctor and have a lot of authority to say that, then

whatever you do is going to be interpreted as "schizophrenic" behaviour. If you get angry, nobody's going to think it's because you have a right to get angry; they're going to think it's a symptom of your illness. If you're down, it's not because you have a good reason to be down; it's a symptom of your illness. And if you kept insisting that you're not ill, that's the most convincing symptom of your illness.

- Q. Why in the world would anybody want to call their organization the Mental Patients Association? (The reference is to the Mental Patients Association in Vancouver.)
- A. There is a reason for calling something the Mental Patients Association, and I think it may be pretty obvious. It's analogous to Dick Gregory writing a book called Nigger. If you're going to call us that, we're going to throw it right back in your face.
- Q. I feel you've blurred the line between medical disease and mental illness. One thing you said was that there's no way of measuring things, there's no identifiable pattern. It seems to me you can't say because you don't know what the symptoms are at this point in time that there's no measureable thing at this point in time, that there isn't some physiological reason other than these normal problems and stresses. Can I just historically point something out? George III was put in a strait-jacket. I shouldn't think anybody would be more privileged than royalty, yet he was restrained. He was said to be "manic depressive". He was bled. But now we know precisely what was wrong with George III; he was a carrier of porphyria, which is now identifiable. I would think there is a danger in suggesting that you wipe out the word "illness" altogether. I can't really accept--having seen many who are mentally ill--that they just have problems, some of them.
- A. Well, let me word it a little differently then. What I'm talking about is the distinction between, let's say, physiological manifestations--something wrong with the mechanism of one's body in some way, including the brain, of course, as part of the body--and behaviour. It seems to me that what we have done as a society is

that we have drawn fairly narrowly the limits of what we consider "normal" behaviour. It's perfectly all right to come to this meeting tonight dressed in a business suit, it's perfectly all right to come dressed in blue jeans, but if you showed up in a bathing suit we'd be a little concerned about you. What we have tended to do is say, "Here are the lines of what we consider to be normal behaviour." If someone is behaving outside those lines, we're not prepared to simply say that this is an eccentric person; we have to somehow say to ourselves that there's something wrong with this person. Now, I grant you some people are a little over the line and some people are very far over the line, and we may not be able to say why they're very far over the line. But I think in a way it's a copout to say they're way over there because they're "ill". They may just be way over there because they're way over there. Now I grant you that your example of porphyria is a very good one--that's something we didn't know about then and we do now. And it may be that tomorrow somebody will be able to say, "Aha, depression is caused by a deficiency of vitamin B12 in the diet." If they do, if somebody can demonstrate it conclusively, I'll be the first to switch sides. But I'm not prepared to start out by saying it's an illness unless somebody can show me. I'm prepared to say it's a behavioural aberration--and probably the result of emotional conflicts rather than of something physical.

- Q. Possibly the emotional conflicts and the amount of stress have produced some physiological effects.
- A. Oh, sure, there's a lot of interrelationship.
- Q. It seems to me the point isn't whether or not mental illness is necessarily physiological; what we're talking about is methods of treatment of people's conditions. It really seems to me that the point you were trying to make was about the prescribing of certain set treatments, when in fact there is no way of estimating whether or not those treatments are what is necessary.
- A. Well, if I can give a very brief personal example When I was hospitalized, I was hospitalized with terribly, terribly severe depression. What I needed, and what finally got me out of there, was somebody to talk to-- somebody to tell why I was upset, to pour my heart out

to. What I got when I first went in was fifteen shock treatments and a lot of Librium. And as far as I'm concerned, that's ridiculous. It's not only ridiculous-- it's criminal.

- Q. I'd like to make a brief point about that. There are two fairly well-respected authorities that have written books that are critical of mental health treatment and diagnosis. One's called The Death of Psychiatry, by Dr. E. Fuller Torrey, who's associated with no less an august body than the National Institute of Mental Health in Washington. He claims that not only is there no scientific proof of any psychiatric diagnosis, but that the diagnostic terms themselves are pejorative, like swearing at people. And there's a lot of day-to-day truth to back that up. Also, Dr. Thomas Szasz said essentially the same thing in The Manufacture of Madness and The Myth of Mental Illness--that psychiatric diagnoses are phony and invalid labels, and he says the same thing in one of his most recent books, Schizophrenia: The Sacred Symbol of Psychiatry. There's no scientific proof that "schizophrenia" exists in the sense of a medical entity, the way diabetes does. He says the same thing as Torrey--that psychiatric diagnoses are ways to discredit people whose behaviour is thought or assumed to be too troublesome for the authorities. So it's a political question.
- A. Torrey points out in one of his books that--to pick up on the pejorative aspect of being labelled "mentally ill"--the only comparable diagnosis in physical medicine is being told you have leprosy.
- Q. It seems to me in thinking about all that you have said about the treatment of mental illness that what we should be doing as a community or as an association is putting a real push on reaching people before they're labelled, before they get to that point where they are institutionalized.
- A. Absolutely.
- Q. We've got to do far more in the community, I think, to make help, or even somebody to talk to--to have that sort of help more readily available.

- A. What I'd like to see as the community's top priorities are: a crisis centre; provision of jobs; provision of housing; provision of a drop-in where people can just come and talk to other people. And a lot of concern about people who are in hospitals too--but those as ways of keeping people from getting in in the first place, and of helping them when they get out.
- Q. I'm fairly ignorant about what's available in Kingston--this is really terrible. I'm usually fairly familiar with social and health services. Can somebody tell me what's the closest we have to a drop-in? Is it the mental health clinic on Barry (?) Street? Or at Kingston Psychiatric Hospital?
- Q. I just wanted to mention the White Cross Centres that are available. I think there's a difference between, for example, Barry (?) Street, which is a diagnostic and treatment centre, and the kind of supportive things you're talking about.
- A. It might be of some interest to you to know that one of the organizations to which I belong in Toronto, the Ontario Patients' Self-Help Association, has been running a small ad in the personal column of the Toronto Sun, just letting people know we're there and telling them where to write for information. We've had letters from Kingston saying, "Please, please, tell me about your group--because there's nothing for us here."
- Q. It seems to me that even if there was one place to call, and some trained counsellors of some sort, we could talk to people as an initial stage, and that could go an awfully long way.
- Q. We don't have a lot of people willing to devote time just to talk to people, as one person talking to another, as someone who can say, "Gee, it looks like you never get out of your place. Why don't you come down to talk to me? Why don't you go out? Here are some things you could be doing. Come on over here and get some fresh air. It's all right--I've had common concerns, I've had some of these problems, you know it's no big deal."
- A. I think it's crucial too. The group I mentioned has as an exclusive principle--it seems to me it should be at least a partial principle--that the people involved

in that kind of thing should be former patients. There is a great sigh of relief in realizing, as you're about to spill your heart out to somebody, that they're going to understand because they've been through it. It's a tremendous help. I discovered when I was working at the Legal Aid Clinic at the Queen Street Mental Health Centre, for instance, that people would come in, and they'd be terribly embarrassed and humiliated that they were in this awful place, and they'd been labelled "mentally ill", and now they were going to have to talk to a law student. And when the law student said, "Hey, it's all right--I know, I was here too," the whole atmosphere just changed.

WRAP-UP STATEMENT:

Carla, at this point I think we've got a lot of things to talk more about from what's come out of your talk. I think one of the main things you've pointed out to us is that the myth that mental illness is an "illness" creates a notion in the community that people who are having problems like that are being taken care of in institutions, and I think Kingston is an excellent example of a place where we have many professionals, many institutions. And perhaps that myth has prevented the kind of discussion and development needed of community support systems to keep people from ending up in them. So I'd like to thank you very much for what you've had to say so far, and suggest that later on in the evening we break into small groups and continue this discussion. Thank you.